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AUTISM AND THE FOSTER CARE SYSTEM IN KENTUCKY

A Capstone Experience/Thesis Project Presented in Partial Fulfillment
of the Requirements for the Degree Bachelor of Science
with Mahurin Honors College Graduate Distinction
at Western Kentucky University

By

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May 2021

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ABSTRACT

According to the CDC, one in 59 children are diagnosed with Autism Spectrum Disorder (Centers for Diseases and Prevention, 2020). More than 10% of those in the foster care system also have an autism diagnosis. The purpose of this project was to understand the general public's knowledge and beliefs about both subjects. I conducted this study to identify any misconceptions, assumed facts, and opinions about both foster care and autism. I collected these data through anonymous surveys. The data were then analyzed and examined to create an app to benefit current and future foster parents who foster individuals with autism.

I dedicate this thesis to my mom and dad, who continually inspire me. I would not be where or who I am without their continual love, support, and illustration of what selflessness and hard work look like.

ACKNOWLEDGEMENTS

This project would not have been possible without the help of many people. I would like to thank my parents, Brad and Holly Clark, for their unwavering support and love. I would like to thank my sisters, Sarah and Mia. Thank you for fundamentally shaping the way I think and act, and for teaching me how to be kind, patient, and intentional. I would also like to thank all of my additional friends and family who supported me throughout this process.

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INTRODUCTION

Over one in 59 individuals are diagnosed with autism, and over 10% of those in foster care are on the Autism Spectrum (Mandell, 2018). The two clearly overlap, which is why it is important to research both subjects, not only separately, but also together. This project aims to identify and analyze the connection between foster care and autism and implications for practice. This project has three research questions:

- (a) “What does the general public believe about foster care and the autism spectrum?”
- (b) “Is taking a child with a preexisting autism diagnosis daunting for foster parents?”
- (c) “What do people need to feel more comfortable with fostering and accepting children with an autism diagnosis?”

These questions were answered through the administration of a detailed survey that consisted of questions to truly assess both public understanding and opinions about (a) fostering, (b) autism, and (c) fostering with autism.

It was hypothesized that the general public had little to no understanding, as well as many misconceptions when it came to individuals with autism. Autism is intimidating and challenging; caring for a child with autism takes hard work and perseverance. The same could also be said about the foster care system. Foster care can be wonderful, but it is complex and cloaked with law, rules, regulations, and stigma. Therefore, it was also hypothesized that the general public had little to no understanding of how such an integral system in our society worked.

BACKGROUND

Foster Care in Kentucky

Kentucky has had a unified court system since 1975, and in 2002, a Family Court division of Circuit Court was created (Bingham, 2018). A child from birth to eighteen can be placed in the foster care system, but there is a lengthy process that must take place in order for an individual to enter said system. When an agency, school, or third-party candidate presents a reasonable cause to believe that a child or dependent is being abused or neglected, The Department for Community Based Services (DCBS) is primarily the investigative agency. The preferable option is to keep the child at home or with the family with close supervision and observation. The goal of the foster care system is to reunify the child back with the parent or guardian, and this goal is established even before the child is under state jurisdiction. With that being said, if the home environment and surrounding persons are too detrimental to the child and the DCBS believes that the child is in danger, then a petition to the District Court must be made. This action is made for children who are being abused or neglected, or “DNA” cases, which stands for “Dependent, Neglected, or Abuse.” In the Kentucky legal system, “neglect” is defined as a situation where the parent, caretaker, or custodian does not adequate or effective take care of the child and their needs, while the courts working definition of “abuse” is when a parent, caretaker or guardian is physically or emotionally harming the child, or is allowing someone to physically or emotionally harm their child (*“General information about child abuse and neglect”*, 2008). Examples of this would include, but are not

limited to: sexual abuse, educational neglect, alcohol or drug induced incapacity, incarceration and felony conviction, and mental illness or deficiency.

Once the child's case has been deferred to the District Court, several things may happen. If a child cannot be located or the parents or guardians deny the cabinet access to the child, the judge may issue a search warrant to a law enforcement officer to further investigate. However, if it is believed that a child is in immediate and extreme danger, a law enforcement officer may remove a child and then request an emergency custody order (EPO) within twelve hours of the removal. After an EPO, a temporary hearing must be held within 72 hours of the issuance of the emergency custody orders. This hearing is to determine if the removal was appropriate, and if the courts find that the removal was in fact necessary, then the child will be placed in the least restrictive non-parental placement. This could mean aunts, uncles or other relatives, as well as the DCBS, or other appropriate agencies. The child will stay with this placement until a full and proper adjunct hearing takes place, which must be within 45 days of the child's removal. The adjunct hearing addresses the original reason for removal, and this is where the court judges if a child is being abused or neglected. If the court finds the allegations incorrect, then the child is returned home. If the courts find that the child is being abused or neglected, then a dispositional hearing occurs, and the child receives an official placement.

While a child is in foster care, both federal law and state law require a case plan to be put in place. The U.S. Department of Health and Human Services defines the Case Plan as "a written document that is developed jointly with the parents or guardian of the child in foster care" (U.S. Department of Health and Human Services, Administration of

Children, Youth, and Families Children's Bureau, 2018). In short, this is a document detailing what the child needs, what placements would best serve a child's interests and special needs, as well as the steps a parent needs to make in order to reunify with their child, if a Case Plan's goal is reunification. A parent must adhere to a child's Case Plan in order to reunify with their child, and this plan will be reviewed by the courts annually. If a parent does not make any steps to alleviate the plan, then the process of terminating parental rights may move forward so that the child may be adopted.

Autism

Autism is a neurodevelopmental disability (Centers for Diseases and Preventions, 2020). There is no single identified cause, and there is also no cure. Autism is commonly coined as a "snowflake disorder", where each case is different from the next. However, autism is generally marked by difficulties in social skills, communication, intellectual and adaptive functioning. In the United States, the working definition the schools, psychologists, and other personnel use is from the Diagnostic and Statistical Manual of Mental Disorders. Presently, the one in use is the Fifth Edition (DSM-5). In order to receive an autism diagnosis, an individual must meet all three areas of social communication and interaction deficits, as well as at least two out of the four areas of restricted, repetitive areas. Autism is also a spectrum, and has three levels, where each level increases in severity (Centers for Diseases and Prevention, 2020).

Autism and Foster Care in Kentucky

One in 59 individuals are diagnosed with autism, and over 10% of those in foster care are on the Autism Spectrum (Mandell, 2018). Though there are several reasons that a child may be removed from their home, 53% are removed due to neglect, 41% are

removed due to parental substance abuse, and 16% are removed due to child behavior problems (Williams, 2020). This can be seen in Table 1. Though these may just seem like numbers and percentages, in practice, these data have large implications.

Statistically speaking, 31% of children with ASD have an intellectual disability, anxiety disorders affect an estimated 11 to 40% of those with autism, and depression affects an estimated 7% of children on the autism spectrum (Autism Speaks, 2020). Under the Individuals with Education Act (IDEA), 13 categories of disabilities were categorized. If a student is diagnosed with one of these thirteen disabilities to the point it hinders their educational experience, they are legally entitled to special education services. With all of this being said, as stated above, 53% of children are removed from their homes due to neglect (Williams, 2020). Educational neglect is a large category of neglect, especially in Kentucky. When a child with autism is removed from their home due to educational neglect, this means that the parent or guardian in question has neglected the child's basic educational needs and is, in turn, directly or indirectly affecting the child's normal educational development. Children, especially children with autism, need support systems in place, and studies have concluded that neglected children are at risk for physical, emotional and behavioral disorders in both childhood and adulthood, and are further at risk for neglect later in life, regardless of child welfare intervention (Keeshin & Dubowitz, 2013). This has huge implications for students with autism. When a student with autism is being educationally neglected, a challenging situation becomes deleterious. This is not to say every student with autism is going to need copious amounts of aid, but there is also a reason why autism is one of the thirteen disability categories, and why a system is established to assist those with autism. In the

end, educational neglect is a huge burden on children with autism, not only educationally, but developmentally, and socially.

Furthermore, statistics identify that many who do have autism are also predisposed to having or do have anxiety and/or depression (Tager-Flusberg & Kasari, 2013). This is another key data point in further understanding the implications of those in foster care who also fall on the spectrum. Those in foster care are put in foster care for a purpose, all of which are destructive and dangerous to a child. In Kentucky, before entering foster care, 7% have been physically abused, 5% have been abandoned together, and 3% have been sexually abused (Williams, 2020). The fact of the matter is, children in the foster care system have undergone substantial trauma, and more often than not, children on the spectrum experience these events in a different way. For one, if a child is predisposed to having anxiety and/or depression, as a large portion of individuals with autism are, and then experiences truly horrific things, their anxiety and/or depression is more likely to be triggered. In fact, there is strong evidence supporting the notion that during childhood, physical and sexual abuse as well as emotional neglect increases the development of depression in adulthood (Viatrol et al., 2014). Regardless if a child is predisposed to anxiety or depression, if they are in the foster care system, they are removed from their home for a reason. They are being taken from their family, their friends, and everything they know as their attachment and trust cycle begins to collapse. This is difficult for any one person to navigate, but can be especially challenging for someone on the spectrum. An estimated 30% of individuals with autism are nonverbal, and it is also not uncommon for individuals with autism to have communication deficits (Tager-Flusberg & Kasari, 2013). More likely than not, individuals with autism who are

also in foster care are dealing with devastating consequences, but are struggling to communicate or even make sense of these events. Furthermore, even if they are able to articulate it to another individual, trust is hard to come by for many who have experienced trust being broken over and over again. Foster children often have negative experiences prior to being admitted in the system, which are two large contributors to difficulties with trust and attachment (West et al., 2020).

METHODS

Participants

This study consisted of a total of 115 responses (17% of participants identified as male, while 83% participants identified as female). The participants ranged in age from 18-63. Participants were given the incentive of entering a drawing for a \$50 certificate upon completion of the survey.

Procedures

Participants had to be eighteen or older in order to participate, but the goal of the survey was to see what the general public knew. For this reason, participants were neither targeted nor excluded. The participants completed a survey online using Qualtrics. Surveys were anonymous, and a participant's consent was needed in order to take part in the survey. Surveys were distributed physically through flyers, but also electronically. Data were also collected and stored electronically. This survey focused heavily on both foster care and autism, and there were two parts.

Measures

The first part was composed of true or false questions. There were eleven true or false questions that pertained to foster care, and there were eight questions that had to do with individuals with autism. Participating members then had to choose if the corresponding statement was true or false. The questions were carefully chosen with the aim of painting a full picture of what the average person knew about both topics. Government sources such as the Centers for Disease Control and Prevention, as well as information from the federal courts and Department of Education were consulted for both

questions and answers for this portion of the survey. It was predicted that, as a whole, half or more than half of the true/ false questions would be answered incorrectly for each category.

The second part of this survey consisted of opinion-based questions, and focused on what people were comfortable with, and what they would need more of in terms of fostering an individual with autism. There were seven yes or no questions, and six selected response questions. For this portion, it was estimated that approximately a quarter or more of people who took this survey would be more open to fostering, or fostering someone with autism, if they had more information on how to about the situation, proper training, and resources to utilize.

RESULTS

The first part of the survey consisted of true or false questions. It was predicted that, as a whole, half or more than half of the true or false questions would be answered incorrectly for each category. The results were semi-conclusive with the hypothesis. For the true or false section, there were nineteen questions total. Out of these nineteen questions, there were twelve questions that 50% or more of the participants answered correctly. For the remaining seven questions, less than 50% of the pooling participants answered the questions correctly. When dividing the questions into two categories, foster care related questions and autism related questions, the results are able to be inspected and analyzed further. For the foster care related questions, there were five out of eleven questions that 50% or more of the participants answered incorrectly. For the autism related questions, there were only two out of eight questions that 50% or more of the participants answered incorrectly. These data are represented through Figure 1. The hypothesis predicted that half or more than half of the true & false questions would be answered incorrectly for each category. When looking at the actual data, the hypothesis was only correct for the foster care related questions.

For the second portion of the survey, the questions were opinion based and aimed to assess how the public felt about foster care, autism, and fostering those with autism. For this portion, it was estimated that approximately a quarter or more of people who took this survey would be more open to fostering, or fostering someone with autism if they had more information on how to go about the situation, proper training, and resources to utilize. This hypothesis was consistent with the survey data.

Over half of the participants stated that they had thought about fostering prior to the administration of the survey. With that being said, only 39% of participants stated that they would foster, as shown in Figure 2. Clearly, there is a bridge between individuals thinking about fostering and individuals actually willing to foster, as shown by the continual numerical data. When asked how the foster care system was intimidating, almost 50% of the pooling population stated that the unknown, paired with all of the various laws and regulations of the court system, were major barriers. This can be shown in Table 2. However, as represented in Figure 2, when asked if participants would be more open to fostering with more extensive training and information, the number “yes” nearly doubled, from 39% of the participants saying yes initially, to 64% of participants stating they would be more open to fostering after more extensive training.

It was also hypothesized that among those who took the survey, the conclusions would find that the more training and information an individual received on fostering an individual with autism, the more open they would be to foster an individual with autism. This hypothesis was also supported by the concluding data.

Figure 3 details that, as a whole, more than a third of the participants stated that they would feel unprepared if a child with autism was placed in their home, with only two participants stating that they would feel “very prepared” if this situation occurred. However, when asked if they would be more open to fostering a child with autism if more information, training, and resources were available, more than half of the participants said “yes.” In fact, when participants were asked what they would need to feel more comfortable about fostering an individual with autism, 20% of the data revealed that people just desired more understanding of the foster care system, as well as

autism itself. Tables 3 and 4 also detail that 20% of participants stated that they would feel more comfortable if they knew what resources and personnel were out there for their family and for their foster children. The hypothesis is further supported by data, shown in Table 5. When asked initially what about an autism diagnosis intimidated the public, approximately 30% of participants stated that an autism diagnosis was very time consuming and complex, and an additional 20% added that they believed an autism diagnosis could get very overwhelming very quickly. With this in mind, it is only logical that individuals would want more training and more information, as with more knowledge and exposure, comes comfortability.

Finally, it was also identified that people wanted more hands-on experience with both the foster care system and individuals with autism. When initially asked why someone would be against fostering an individual with autism, over 60% of contenders had the mentality that there was not enough training for either the foster care system and autism, and that there simply was not enough understanding of autism as a whole. This can be seen in Table 6. All of the concluding evidence supported the idea that more information in addition to more exposure increased the levels of comfortability of fostering an individual with autism.

CONCLUSIONS AND IMPLICATIONS MOVING FORWARD

This survey and corresponding data showcase the conclusion that knowledge truly does have power. While the first hypothesis was only semi-correct, the second conclusion was overwhelmingly paralleled to the original hypothesis. Even more than that, even though many of the participants scored higher on the autism related true or false questions than on the foster care related true or false questions, many of the participants still wanted more information, training, and hands on experience with individuals with autism. This, in short, really does highlight the simple fact individuals wanted to know, learn, and understand more.

When looking at the true or false questions from the first section of the survey, there were more questions about autism that were answered correctly. These results may be apparent for several reasons. For one, when the participants were asked if they knew someone who was fostering or had fostered, around 70% said “yes.” When participants were asked if they knew an individual with autism over 90% of the responders said “yes.” These data show that the participants were more exposed to those with autism than those fostering, and with exposure, comes knowledge and understanding. Additionally, statistically speaking on a national scale, there are more individuals on the spectrum than in the foster care system. The U.S. Department of Health and Human Services reports that approximately 400,000 are in the foster care system in America (U.S. Department of Health and Human Services, Administration of Children, 2018). The Centers for Disease Control and Prevention reports that approximately 5.4 million individuals have an autism related diagnosis in America (Centers for Diseases and Preventions, 2020). As prevalent

as foster care is, there is no denying that autism is even more prevalent in America. This unprecedented prevalence could explain why these participants of this survey were more familiar and more knowledgeable about autism than foster care.

When looking at the second part of the survey, the opinion-based questions, there was an overwhelming conclusion in the data. The numbers clearly indicated that as knowledge about both foster care and autism increased, so did the chances of an individual fostering someone with autism. There is a direct link between knowledge and comfortability levels. In adherence to the conclusion of the data set, and the data displayed in Tables 3 and 4, an app was created to both inform and guide past and current foster parents on individuals with autism, and to encourage those hoping to foster an individual with autism in the future. The goal of this app is to use the data collected through the surveys, and directly link it to a path moving forward, and was created with this goal in mind. The information and resources enlisted on the app were collected through a variety of different means and sources.

Moving forward, this will be a tool that foster parents will be able to use to learn more about foster care in Kentucky, federal grants, autism, educational grants and additional third-party funding, and other available resources. This was a small data set, with only statewide results. If additional research was done nationally or internationally, more data would be uncovered and more links between the world of foster care and the world of autism would be able to be drawn.

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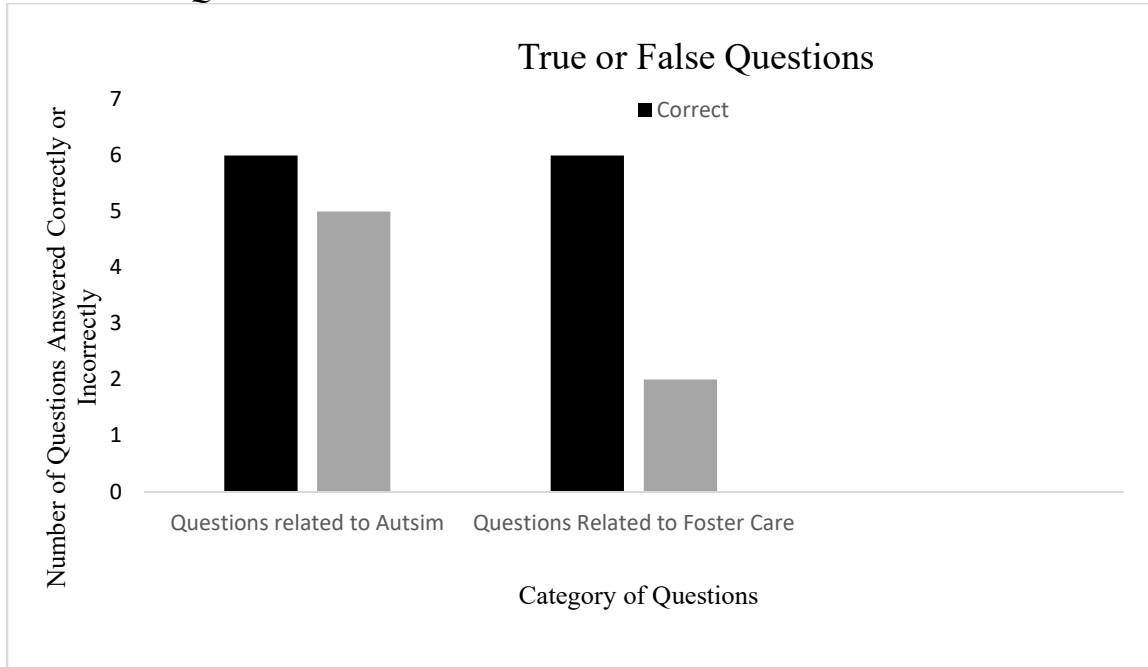
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APPENDIX A: FIGURES

Figure 1.
True or False Questions



Note. In order for a question to be categorized as “correct” or “incorrect”, 50% or more of the participants had to have answered the question correctly or incorrectly.

Figure 2.
Foster Care, Autism, and Training

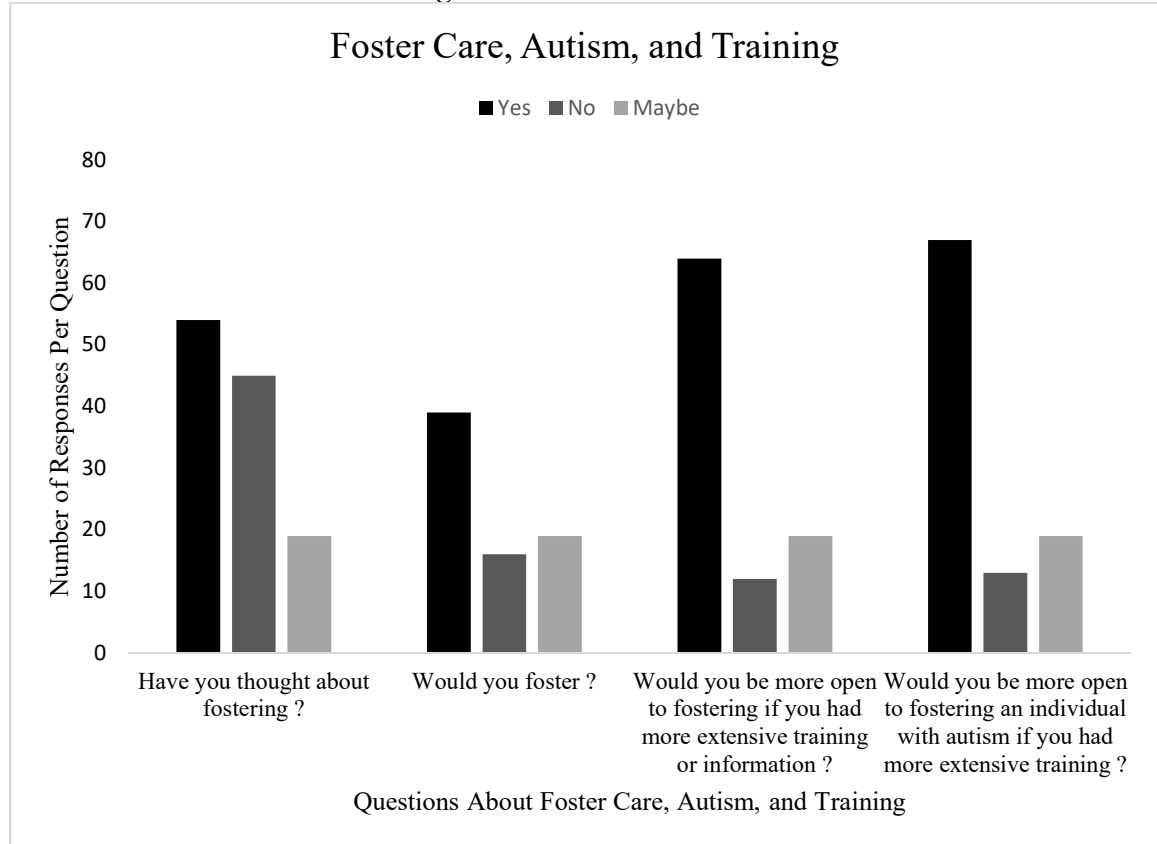
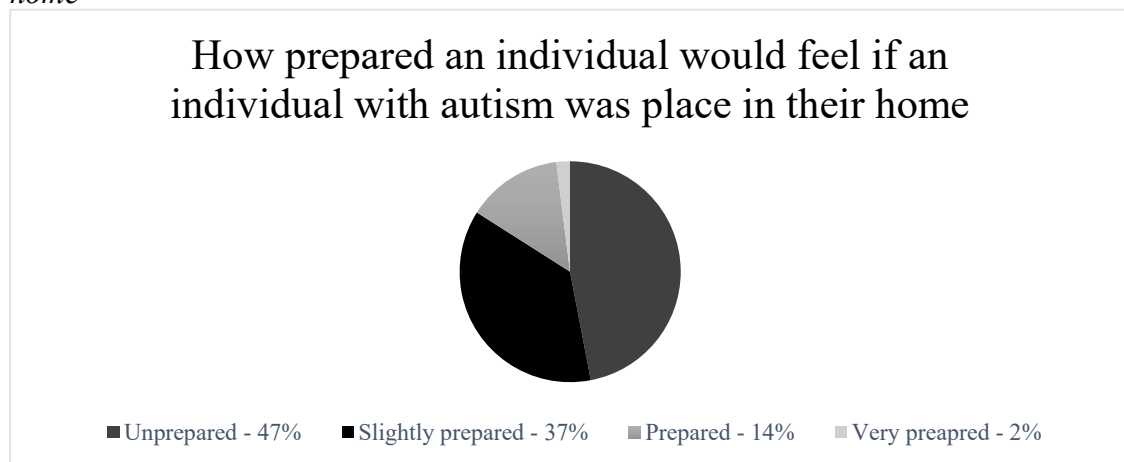


Figure 3.
How prepared an individual would feel if an individual with autism was placed in their home



APPENDIX B: TABLES

Table 1.

Foster Care Entry Reasons in Kentucky

Reason	%
Neglect	53
Parental substance abuse	41
Child behavior problem	16
Inability to cope	13
Inadequate housing	10
Other	10
Parental incarceration	9
Physical abuse	7
Abandonment	5
Sexual abuse	3

Table 2.

Cause of Concern of Foster Care

Cause	Number of Times Answer was Selected
The legal process of it, and all the rules and regulations	62
The unknown	51
The safety of my family	27
I think it is expensive	16
Other	15
I think it is dangerous	7

Table 3.

What an individual would need to feel more comfortable or be more open to fostering a child with autism

Response Options	Number of Times Response was Selected
Training on how to better communicate, handle, help, and assist those with autism	68
More understanding of how the foster care system works, the role and responsibilities of a foster parent, how the court and laws work	61
A list of counselors, occupational therapists, speech therapists, social skills classes, and other points of contact to reference	60
More hands-on experience with individuals who have autism	56
More understanding of what autism is, what it looks like, and how it manifests itself different from individual to individual	55
A detailed list of resources, grants, financial support, and rights available to me through foster care law, special education law, and independent organizations	48
More knowledge of special education law, what that means, and how it can help me	44

Table 4.

What individuals would need to be more comfortable with the idea of fostering, or being more open to foster

Response Option	Number of Times Response was Selected
More understanding of how the foster care system works, the role and responsibilities of a foster parent, how the court and laws work	76
A detailed list of counselors, psychological services, social workers, seasoned foster parents, and other people to contact or enlist when you need help	64
Hands on experience or more exposure to how the foster care system works in practice	54
A detailed list of resources, grants, financial support, and rights available to me when I foster, through independent companies, federal foster care law, and other outlets	52
A more detailed list of requirements and how to meet them	41
More assurance that my family will be safe, or has the option of making sure they are safe through more details about self-defense classes, risk management awareness, and other opportunities such as this	32
More of an emphasis on why fostering is important	14

Table 5.*Causes of Concern for an Autism Diagnosis*

Response	Number of Times Response was Selected
Communication difficulties	46
The work, all of the treatments and therapies and medicine and diet changes seems very time consuming and I don't have the option to be that committed	43
There is too wide a spectrum, and things get very overwhelming very quickly	32
The expenses	24
I think it is dangerous	1

Table 6.*Causes of Concern for Fostering an Individual with Autism*

Response	Number of Times Response was Selected
Not enough understanding of autism	43
Not enough training	42
Not enough resources	27
Not interested	16
Other	9

APPENDIX C: SURVEY

Gender:

Age:

Where do you live:

Part One: Please answer the following questions by checking either *yes* or *no*.

Statement	Yes	No
Are you fostering currently		
Do you know someone who is currently fostering or has fostered		
Do you know someone who is currently fostering or has fostered		
Have you thought about fostering		

Part Two: True or False

The following statements are about the foster care system, laws, and statistics in Kentucky. Based off what you know about the foster care system, please mark whether these statements are true or false?

Statement	True	False
There are over 10,000 youth in foster care in Kentucky		
The goal and purpose of foster care is for the child to ultimately be reunified with their biological parents		
There are more females than males in foster care		
Any child in the system over 14 must legally attend counseling and therapy at least once a month, if not more.		
If a child is in extreme and imminent danger the child can be moved be a cabinet representative without an official court order.		
Foster children legally have rights under the “Bill of Rights for Children in Out-of-home Care.”		
Under Kentucky law, abuse and neglect are essentially the same.		
Around 35% of those in foster care in KY are reunified with their parents.		
In 2016, there were over 100 reports of foster children hurting their host homes parents/ families/friends/ pets.		
Once a child is removed from their home, a full hearing must take place within 30 days of the removal.		
“Risk Factor and Prevention Act” states that a foster family is legally not allowed to foster any males over fifteen if they have any children four and under in the house.		

Statement	True	False
1 in 59 individuals have an autism diagnosis.		
Over one half of children with autism are nonverbal		
Vaccines are one of the leading causes of autism		
Almost 45% of those diagnosed with autism have an intellectual disability and are eligible for special education services under IDEA		
More than half of 25-year-olds with autism have held a paying job		
Medical treatments and services are covered by insurance companies in every state in the United States		
In 2016, there were over 500 cases of autistic individuals who endangered or threatened someone physically or with force.		
According to Autism Speaks, autism treatments and therapies cost an estimated \$80,000 a year through childhood.		

Part Three – Yes or No

- 1) Have you thought about fostering (Y/N)
- 2) Have you ever fostered an individual with autism (Y/N)
- 3) Do you know someone with autism (Y/N)
- 4) Would you foster an individual with autism (Y/N)
- 5) Would you foster (Y/N)
- 6) Would you be more open to fostering an individual with autism if you had more extensive training (Y/N)
- 7) Would you be more open to fostering if you had more extensive training or information ? (Y/N)

Part Four - Multiple Choice

- 8) If an individual with autism was placed in your family, how prepared would you feel
 - a. Not prepared
 - b. kind of prepared
 - c. prepared
 - d. very prepared
- 9) If you would be against fostering an individual with autism, list your reason (s)
 - a. Not enough understanding of the autism
 - b. Not enough resources
 - c. Not enough training
 - d. Not interested
 - e. other

- 10) What, if anything, intimidates you about foster care? (you may choose more than one)
- a. The legal process of it, and all the rules and regulations
 - b. The unknown
 - c. The safety of my family and the potential of receiving a child with in-depth problems
 - d. I think it's dangerous
 - e. I think it's expensive
- 11) What, if anything, intimidates you about an autism diagnosis?
- a. The expenses
 - b. The work, all of the treatments and therapies and medicine and diet changes seems very time consuming and I don't have the option to be that committed
 - c. I think it's dangerous
 - d. There is too wide a spectrum, and things get very overwhelming very quickly.
 - e. Communication difficulties
- 12) What would you need to be more comfortable with the idea of fostering, or be more open to fostering ? Check all that apply.
- a. More understanding of how the foster care system works, the role and responsibilities of a foster parent, how the court and laws work,
 - b. Hands on experience or more exposure to how the foster care system works in practice
 - c. A more detailed list of requirements and how to meet them
 - d. A detailed list of resources, grants, financial support, and rights available to me when I foster, through independent companies, federal foster care law, and other outlets.
 - e. More of an emphasis on why fostering is important
 - f. More assurance that my family will be safe, or has the option of making sure they are safe through more details about self-defense classes, risk management awareness, and other opportunities such as this,
 - g. A detailed list of counselors, psychological services, social workers, seasoned foster parents, and other people to contact or enlist when you need help.
- 13) What would you need to be more comfortable or open with the idea of fostering an individual with autism? Check all that apply.
- a. More understanding of how the foster care system works, the role and responsibilities of a foster parent, how the court and laws work,
 - b. More understanding of what autism is, what it looks like, and how it manifests itself different from individual to individual
 - c. More hands-on experience with individuals who have autism
 - d. A detailed list of resources, grants, financial support, and rights available to me through foster care law, special education law, and independent organizations.
 - e. A list of counselors, occupational therapists, speech therapists, social skills classes, and other points of contact to reference

- f. More knowledge of special education law, what that means, and how it can help me
- g. Training on how to better communicate, handle, help, and assist those with autism

Survey Answers

1.

A) True B) True C) False D) False E) False
 f) False G) True H) True I) True J) False
 K) False L) False M) False N) True

2.

A) True B) False C) False D) False E) True
 F) True G) True H) False I) False J) True
 K) False L) False M) True N) False